



Alabama Department of Rehabilitation Services

CRS *PARENT CONNECTION*



SPRING 2018

My experience with the AMCHP Leadership Lab

by Vera Spinks, CRS parent consultant

As a family leader working at CRS, I'm so thankful for the Association of Maternal and Child Health Programs' (AMCHP) commitment to develop and strengthen maternal and child health (MCH) leaders. The definition of an MCH leader is one who inspires and brings people together to achieve sustainable results to improve the lives of the MCH population. Leadership ability grows as the knowledge, skills, and experience of the individual broaden as they develop from self to others to the wider community.

One leadership development opportunity AMCHP offers is the Leadership Lab. The lab launched in 2015 and is structured to allow family leaders, new Title V and MCH directors, children and youth with special health care needs (CYSHCN) directors, next-generation MCH leaders, and MCH/Title V epidemiologists to learn from each other.

In December 2016, I was accepted as one of six family leaders in the U.S. to participate in the Leadership Lab Family Leader Cohort. The 10-month program required me to attend the 2017 AMCHP annual conference in Kansas City to meet other Leadership Lab participants.

I grew as an individual by just accepting the invitation. For the first time in my life, I traveled – not as a group – but on my own.



Spinks with Edward Esbeck, youth leader and 2017 Ryan Colburn Scholarship recipient

I feared everything that could possibly go wrong, but I took the assignment as a way to conquer my fears. The experience is meant to stretch us after all, and I was fully committed.

I knew I'd gain leadership skills from the experience, but I did not anticipate the greater impact of the conference on me as a family leader. I often refer to myself as "just a parent" who advocates for families of CYSHCNs. After the conference, however, I started seeing myself as an intricate part of a much larger group where each member contributes to create something big together.

One of the conference highlights was hearing from Eileen Forlenza, the first family leader to serve as AMCHP president. In Forlenza's speech, she spoke on the importance of inspiring a shared vision to enable and encourage others. The AMCHP conference gave me a strong vision of family leadership, and it was pivotal in propelling me to be a voice for Title V families in my community, my state, and around the nation.

Leadership Lab activities really accelerated after returning home from the conference. I was in a mentor/mentee group with two family leaders from Virginia and Wisconsin, and we worked together to develop a personal leadership development plan to set goals for the next year. In developing this plan, one of the questions was, "**What is your personal leadership vision?**" I shared my vision of providing better services and support in our Title V program. I want to create a workplace environment of excitement for families of CYSHCN and a desire to help them find "the good life" I feel they deserve.

What I most enjoyed about my experience with the Leadership Lab was making connections and developing relationships with a group of MCH/CYSHCN change

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Parent Connection is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

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From the Director's Chair



Hello Parents, Caregivers, and Families,

There have been quite a few district supervisor staff changes in the CRS program over the past six years, primarily because of retirements. Since 2012, new district supervisors have been named in Anniston/Gadsden, Birmingham, Mobile/Jackson, Dothan/Andalusia, Montgomery/Opelika and Huntsville/Muscle Shoals. And more changes have occurred or are in the works, with one additional replacement, an upcoming replacement scheduled, and a change in the CRS medical consultant position.

Glenda Vansandt became the new **Tuscaloosa/Selma CRS** district supervisor Jan. 16, 2018. Ms. Vansandt completed her master's of social work internship with CRS in 2006 at Tuscaloosa CRS, then started her career in the private sector as a social worker for people with kidney disease. In June 2010, she was hired as a CRS social worker. Since that time, Ms. Vansandt has served as a social work specialist, working with the transition population and most recently as a social work administrator. We are excited to have Glenda in the role of district supervisor and to hear of her plans for making continuous service delivery improvements in the Tuscaloosa/Selma district.

Randy Hebson was named the supervisor for the Birmingham office of Crippled Children Service (CCS) in 1991, after serving 11 years as a CCS social worker. Prior to that, he had served four years at what is now the Department of Human Resources (DHR). Crippled Children Service later became Children's Rehabilitation Service (CRS), and Randy's job classification was changed to district supervisor. In a letter to Birmingham staff as he started his leadership journey, he wrote, "I ask for your patience, understanding, and the chance to reach the potential we know we have here in Birmingham." He further added, "We cannot direct the wind – but we can adjust the sails." When the two Birmingham offices were split into separate districts some 15 years ago, Randy remained as Homewood CRS district supervisor, overseeing the larger, community-based office. However, the statements written so many years ago catapulted the district into what it is today as the potential to "adjust the sails" has been repeated over and over as new clinics and strong community relationships blossomed. Randy will be retiring July 1, but his leadership impact will live on. We offer sincere thanks for his dedication to the district as well as his significant contributions to the CRS Administrative Team and statewide CRS.

Dr. William Watson was appointed CRS medical director/consultant in 1988 and has served in that capacity for a combined total of some 30 years. He first provided care in a CRS clinic in 1976, when he served jointly in the Cerebral Palsy Clinic in Dothan with an orthopedist from Southern Bone and Joint. Later, Dr. Watson would provide clinic services in Montgomery/Opelika Seizure clinics, as well as the Cerebral Palsy, Seizure and Neuro-Ortho clinics in Dothan. On July 1, 1999, Dr. Watson began sharing the medical consultant role with a UAB pediatrician due to a Medicaid administrative rule change requiring a "full-time specialty physician on staff." Eventually, Dr. Watson expanded his role and committed to be the sole physician available to support the CRS program during normal business/working hours. Over the years, Dr. Watson's role as a clinic physician expanded to cover Troy Seizure clinic (Montgomery CRS) as well as clinic coverage at Andalusia CRS, which is a part of the Dothan CRS district. As CRS developed more neurology-related clinics and as other pediatric neurologists moved in and out of the state, Dr. Watson's support of CRS remained constant as he filled gaps in areas wherever pediatric neurology coverage was needed. Today, in addition to continuing coverage in Montgomery/Opelika and Dothan/Andalusia, Dr. Watson provides clinic services to CRS families in Anniston/Gadsden and Mobile/Jackson.

Dr. Watson's contributions to the CRS program have been legendary! His support to clients in clinics, field staff, the CRS Administrative Team, and as medical liaison will be missed greatly as he moves into full retirement April 30. Our sincere thanks go out to Dr. Watson as he prepares to take on new adventures and spend more time with his wife, Mitzi, and his family and friends!

In the next edition of the newsletter, I will share details about the new Homewood district supervisor and the new physicians covering Dr. Watson's clinics and serving as medical consultant.

Melinda Davis, CRS Director



Mobile CRS creates private Facebook group for parents

by Jessica Havard, CRS parent consultant

We live in a technology-driven time, and pretty much everything is available at the click of a button or the swipe of a finger.

When I started as parent consultant in Mobile's CRS office, I wanted to find a way to incorporate and take advantage of technology in my outreach. After thinking about it, I decided that Facebook was the way to do this, especially considering that a good portion of today's parents use Facebook at least once a day.

The Mobile CRS Parents Facebook Group is a safe place for Mobile-area parents of children with special health care needs to visit and share their successful stories, questions, or grievances without ever having to leave home. Valuable information on upcoming events, trainings, and PAC meetings is posted, along with disability-related resources and websites



for the group. Parents are encouraged to join in to discuss and ask any questions they may have.

The Mobile CRS Parents group is a closed group, meaning that only group members can see or respond to posts. Persons requesting to be group members are asked: *1. Are you a parent or*

family member of a child with special health care needs? 2. Do you receive services from CRS? and 3. What can I do to help?/What information are you looking for?

To join the group, visit: www.facebook.com/MobileCRSParentsGroup.

AMCHP

Continued from Page 1

agents. Networking is one of my "love languages" and this spoke to my heart as a family leader.

My lab experience focused and encouraged me to set a personal leadership development plan that built my confidence and refined my MCH leadership competencies. I also became more involved in policy and advocacy.

I was sad when my lab experience concluded, but was elated that CRS Director Melinda Davis invited me to attend this year's AMCHP conference in Washington, D.C.

When I returned to the conference, I didn't have fears like I did the year before. I expected another great experience based on everything I knew from last year.

It's hard to narrow my list of takeaways from the many great sessions I attended, but Dr. Richard Antonelli of Boston Children's Hospital would have to be at the top. Antonelli said we have to reach families, and he knows from his professional experience that a medical home is necessary, but it isn't sufficient on its own for children or youth with

special health care needs.

When he said this, it "charged" to me to find out more about Title V and the ways we work to make the medical home sufficient for CYSHCN and provide critical family-to-family support.

Another important takeaway was a session on MCH policy engagement. In that session, we brainstormed potential improvements to developing policies and procedures using national performance measures. CRS is focusing on a new policy to improve youth transition, and I could see how this tool could assist in the process.

With the conference in Washington, D.C., an obvious advantage is the ability to schedule visits with our lawmakers. Advocating and educating Congress on CYSHCN and MCH needs is at the core of leadership competency.

CRS State Parent Consultant Susan Colburn and I each visited the offices of Sen. Doug Jones, Sen. Richard Shelby, and Rep. Terri Sewell. It was exciting to witness democracy in action, and the experience reminded me that policy is made where advocacy is needed.

Advocacy happens all around us. It happens in administrations and in Congress. At the state and local levels. It occurs at home, at the workplace, and abroad.

In our meetings with Congress, we partnered with Family Voices of Alabama to share personal stories with handmade Valentine's cards sharing each family's health care wishes. I also printed pictures of my children for each member of Congress to represent the importance of Title V and all systems of care.

We built relationships with our lawmakers through these meetings, and I hope that when they make future decisions, they remember the stories we shared with them. Every family's story matters, and we can impact policy by sharing those stories.

It has been an honor to take part in the Leadership Lab and attend AMCHP's conference twice in as many years. In the next year, I strive to further develop myself professionally and embody the very definition of an MCH/CYSHCN family leader. Continuing to partner with Alabama's families and professionals will make this a reality.



Ready, set, transition ...

by Ree Clark, CRS parent consultant

There are times when I feel like we're barreling towards transition at neck-breaking speed. I'm not entirely sure that I'm ready for everything it entails.

Now, I've had 15 years to prepare and practice for it with my son, Alex. But when I think about the areas transition involves, it becomes overwhelming. There are several challenges to consider: moving from pediatric to adult primary care, from CRS client to VR consumer, from high school to work/college.

Recently, I had an epiphany: **Transition is a process.** It's not this be-all-end-all event in someone's life. However, it is of great importance to us as parents and caregivers because we need to prepare our loved ones for adulthood. With some planning and research, you should feel assured that your teenager or young adult with special health care needs is prepared for success in his/her future.

As the CRS parent consultant for the Montgomery office, I've heard many concerns from parents who were completely unprepared for transition. They suddenly needed a primary physician and couldn't find one; they anxiously pondered what to do for loved ones exiting school; they wearily searched for suitable day programs or job placements. Often, parents would find out too late that day programs were



Ree Clark's 15 year-old son, Alex, is just beginning his transition journey

unavailable, inaccessible, or not feasible, leaving them at a loss.

I had already pondered many of these transition-related issues when an influx of calls added to my thoughts and concerns. Just last week, in fact, I was asked by my son's social worker if he was ready for Teen Transition Clinic and a vocational rehabilitation counselor.

Alex is in the 9th grade and has orthopedic issues and learning disabilities related to his syndrome. Having a disability that affects so many aspects of life and causes developmental delays is challenging in many ways. Its effects reinforce the need for a plan and preparedness. While I decided Teen Transition Clinic is not immediately appropriate, I took significant time to review our game plan. **Preparation is everything.** Having concrete goals throughout the process will greatly reduce potential stressors.

My son still sees a pediatrician, but it's been helpful for us to also use a local urgent care clinic for check-ups and minor illnesses. Doing this has been a great way for my son to learn to speak up for his own needs. I've pridefully watched my son explain his needs to the doctor. Allowing this also builds self-advocacy and language skills. His pediatric office is still a wonderful place, but knowing my son isn't overwhelmed with quiet early mornings spent at the urgent care clinic is also wonderful.

Alex also uses his new advocacy skills to share his future dreams and goals. My son has known his employment goal for many years: He wants to own

and operate a pizzeria. Sometimes, well-meaning people will hear him talk about it and ask if he intends to work at a pizza restaurant. He always replies, "No, I plan to own it." He's even decided on a name: *Alex's Pizza Palace*.

Nationally, there are many examples of individuals with disabilities who are also business owners. It often takes community support and family involvement, but it certainly isn't automatically out of reach. Look at Amy Wright, CNN's 2017 Hero of the Year. She was recognized for her advocacy and ownership of *Bitty and Beau's*, a coffee shop which employs 40 individuals with various physical and intellectual disabilities. Another example is the Prospector Theater in Connecticut. Founded by Valerie Jensen, who has a sister with Down syndrome, the theater represents Jensen's desire to provide opportunities for persons with disabilities to have meaningful employment. These parents and caregivers inspire me. Having a disability should not negate having big dreams.

Community support and resources mean everything. CRS provides a Teen Transition Clinic to help teens consider future options regarding career choices, education, employment opportunities, health care models, and independent/community life. Vocational Rehabilitation Service is the go-to resource for job placement assistance. Having access to the right tools can develop a heightened degree of independence and opportunity.

Of course, parents can also work with community, state, or national resources external to ADRS. Family Voices of Alabama, local independent living centers, and Easter Seals of Alabama are all great resources that parents can rely upon for support and services in developing an adequate transition plan.

Transition plans are as unique as the individuals they serve. Where one person's plan may include college, another's might be owning a restaurant. A third plan might include doing both. I've accepted this as part of the transition planning process. There are many opportunities to consider for my son, but it no longer overwhelms me. Instead, I choose to see it all as an invaluable gift.



Alex, left, helps bake cookies at home

Meet Homewood CRS's new parent consultant

by Amanda Chandler, CRS parent consultant

Hi! My name is Amanda Chandler, and I'm the parent consultant for Homewood CRS. I've just completed my first year as part of the team here, and I'm looking forward to meeting even more families in the next year.



Chandler takes notes during the 2018 Medical Aspects of Disabilities Conference

Like all of our parent consultants, I have children with special health care needs. My oldest, Myers, struggled for years with global dyspraxia, chronic ear infections, and some specific learning disabilities. My daughter, Gracie, has ADHD, asthma, and major depressive disorder. My twin boys, Aiden and Xander, were born a month early. They aspirated meconium as newborns and had hearing loss and other medical challenges that placed them in the NICU.

Aiden came home from the hospital after only a week, but Xander stayed for 71 very long days. With both boys finally home, we began the arduous journey of caring for these two tiny humans.

I first learned about Children's Rehabilitation Service after the twins were born in 2008. As we already had kids, my husband and I thought we had the parenting thing all figured out. However, the boys' unique health concerns suddenly placed me in desperate need of additional guidance.

My CRS journey began in the Feeding

Clinic. Eating is one of the most basic skills for any parent, but Xander struggled. We accommodated his weak sucking reflex and laryngomalacia with CRS Nutritionist Claire Stephens' help.

Xander's infantile spasms began at five months of age. We quickly learned we would need loads of help caring for this little boy. Whether right or wrong, Aiden's hearing loss took a back seat to Xander's life-and-death fight with West syndrome.

With a new diagnosis, we learned that Xander needed a feeding tube. We again turned to CRS, and they helped us track his weight and manage his bolus schedule to achieve his optimum health.

When Xander's care became more stable, we were able to devote more time to face Aiden's challenges. Physically, he was right on target, but he wasn't showing any talking signs. After more testing, we found a progression of hearing loss in Aiden's left ear. Aiden got tubes in his ears and began working with a speech therapist through Alabama's Early Intervention System (AEIS). An AEIS occupational therapist also addressed his hypermobile joints and fine motor challenges.

When I look back on those difficult and trying times, I laugh whenever I think about Aiden's speech-language pathologist (SLP), who asked if I ever had any "normal" children? I guess I didn't, but it's OK because normal is overrated!

Years later, we found ourselves facing the reality that Xander would not be able to speak with us or his siblings as we once had hoped. Again, CRS stepped in to help him find his voice. CRS SLP Karen Baggett helped him get jelly bean switches to allow him to communicate choices and share recorded messages during school's circle time. He took a more active role at circle time with his friends, and it always brought a smile to his sweet face.

CRS also asked about other equipment needs for our family. We found ourselves desperately needing a new car seat and bath chair. Billy Ronilo, CRS physical

therapist, came to our home to measure for a bath chair, and he ordered Xander a better fitting car seat than what we had.

Like so many other families, we found that having children with special health care needs was isolating. Our friends and family just couldn't relate to the traumatic experiences we faced. Little by little, many of those friends faded into the distance as they watched quietly, not knowing what to say. The CRS office was one of the few places that greeted me with understanding. I didn't have to explain our challenges, and our CRS friends celebrated the victories with us. There will never be a day that I won't appreciate the support, care, and engagement of the entire team who helped Xander and Aiden on their way.

Sadly, we lost Xander in October 2015. It took a full year before I was ready to return to work. But when I did feel ready, I reached out to my friend at Tuscaloosa CRS, Vera Spinks. She's the parent consultant there, and she told me about the position open in Homewood.

I'm so happy and thankful to be a part of the CRS family. It's a blessing to be able to engage with other families as they learn to embrace their own "new normal" and navigate the myriad of social services, equipment distributors, and the medical industry as a whole. Our family soon discovered the meaning of "it takes a village" when we entered this brave, new world. Thank you so much for allowing me to be part of your village. I'm looking forward to seeing where you'll take us.



Xander, as the 'Little Engine that Could' at his kindergarten graduation

For more information about Children's Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at rehab.alabama.gov/CRS and www.facebook.com/CRS.ParentConnection

Partners in Care Summit set for May 3-4

Family Voices of Alabama, home to Alabama's Family-to-Family Health Information Center, is excited to be hosting our ninth annual Partners in Care Summit at the Montgomery Marriott Prattville Hotel & Conference Center at Capitol Hill, May 3 and 4. The Partners in Care Summit is sponsored in collaboration with Children's Rehabilitation Service.



As in past years, the first afternoon is only open to youth and families. This is a critical time for them to network while developing skills they can take back to their communities and use to impact the various systems they are a part of.

The Full Life Ahead Foundation leads this year's youth session, entitled *Kicking Transition*, where individuals who are 18 and older will interact to learn about transitioning to a full adult life.

Dr. Renee Turchi, associate professor in the Department of Pediatrics at Drexel University College of Medicine in Philadelphia and parent leader LaQunna Williams will lead the parent's afternoon session, *Using/Developing a Care Map and Building Partnerships While Advocating for Your Child/Youth*.

The summit's second day is an all-day workshop designed to give families and youth and the professionals who work with them an opportunity to learn together, network with each other, and identify



Julie Beckett, Family Voices co-founder, speaks at last year's Partners in Care Summit

strategies to help improve outcomes for children and youth with special health care needs.

Dr. Turchi and Williams will deliver the summit's keynote on family engagement, and Jeanne McAllister, associate research professor of pediatrics at the Indiana University School of Medicine, will deliver a session on care coordination.

This year's Partners in Care Summit will also feature the Super Parents exhibit, which was highlighted on CNN. In 2016, the Lucile Packard Foundation for Children's Health enlisted Pulitzer Prize-winning photographer Deanne Fitzmaurice to document the lives of a families with children with special health care needs. Fitzmaurice shadowed 10 California families with CYSHCN. The children, aged 2 to 21, have diagnoses ranging from Type 1 diabetes to spina

bifida to neurofibromatosis.

More information on the conference is available at www.familyvoicesal.org. Please mark your calendar now and make plans to join us this May.



The second day of the conference is filled with information for families, youth, and professionals from national presenters who aim to improve the medical home

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For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, susan.colburn@rehab.alabama.gov, or Jerry Oveson at 251-438-1609, oveson@bellsouth.net.

CRS receives grant to advance care for children with medical complexity

Collaborative Improvement and Innovation Networks (CollNs) are multidisciplinary teams of federal, state, and local leaders working together to tackle a common problem.

Last year, CRS was one of 10 states awarded a CollN to advance care for children with medical complexity (CMC). The grant, managed by the Boston University School of Public Health and supported through the Health Resources and Services Administration (HRSA), is to improve the quality of life for children with medical complexity, the well-being of their families, and the cost effectiveness of their care.

The CollN approach provides a way for participants to self-organize, forge partnerships, and take coordinated action to address complicated issues, said Lolita McLean, CRS maternal and



CRS Maternal and Child Health Coordinator Lolita McLean assists in managing the CollN for children with medical complexity

child health coordinator.

"The core of the problem we are working to solve is developing and testing a new pay model for care of children with medical complexity. It is a very small

group of children – less than 1 percent – but their significant medical needs use up a majority of the total funding," said McLean.

In addition to helping identify a new CMC pay model, CRS will work to reduce scheduled CMC hospitalizations and also report unmet needs of children with medical complexity.

Other states participating in the CollN are Colorado, Indiana, Kentucky, Massachusetts, Minnesota, Oregon, Texas, Washington, and Wisconsin. CRS will receive \$135,000 in funding per year through 2021 for participating in the CollN.

Other partners in the HRSA-supported CollN include the American Academy of Pediatrics, the Association of Maternal and Child Health Programs, and Family Voices.

Huge 'GIFT' for families



The inaugural Growing Independent Families Through Support (GIFTS) conference took place at Eufaula's Lakepoint Resort in January. The free conference invited caregivers, parents, nurses, social workers, first responders, and educators to learn about Medicaid Waivers, Project SEARCH, Alabama Lifespan Respite, Charting the LifeCourse, and more. The GIFTS conference was sponsored by ADRS, the Alabama Council of Developmental Disabilities, and the Dothan Parent Advisory Committee.

BREAKING NEWS

Children's Rehabilitation Service is pleased to announce that Courtney Adams and Sarah Williams have just been selected as our new state youth consultants. As CRS youth consultants, their duties will include serving as State Office team members, providing leadership to the CRS Youth Advisory Committee (YAC), participating in local CRS office youth activities, and sharing transition information and resources with youth with special health care needs. Courtney Adams will be serve in the Dothan CRS office, and Sarah Williams will serve in Montgomery. Please join us in welcoming them to the CRS family.



Autumn made a Springtime Hero

Autumn Tidmore was named March Hero of the Month for Birmingham CRS's Cystic Fibrosis Clinic. Cystic fibrosis is a life-long illness of the lungs and gastrointestinal system. While there isn't a cure, therapies greatly improve quality and length of life.

Autumn is a hero for her positive attitude and daily commitment to chest physical therapy and medication adherence. She sets an excellent example to peers at school and in the cystic fibrosis community.





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Check Out What's Ahead ...

May 3-4, 2018

Partners in Care Summit

Description: Family Voices of Alabama and the Family to Family Health Information Center project will host the ninth annual Partners in Care Summit at the Montgomery Prattville Hotel & Conference Center at Capitol Hill in Prattville.

Information: 1-877-771-3862

June 1, 2018

Opelika CRS School's Out Bash

Description: Free event for children and families served by Opelika CRS with carnival atmosphere to celebrate summer vacation. Includes area vendors and resources for families with children and youth with special health care needs.

Information: Sharon Henderson, (334) 705-2015, 1-800-568-8428, or sharon.henderson@rehab.alabama.gov

Oct. 15-17, 2018

2018 Early Intervention & Preschool Conference

Description: A two-and-a-half day event designed to share information and develop skills for professionals and families who work with children with disabilities from birth to 5 years of age. The conference will be held at the Sheraton Birmingham Hotel.

Information: Jeri Jackson, (334) 293-7088, jeri.jackson@rehab.alabama.gov

Local PAC meetings: Check your local CRS office for dates and times of meetings in your area.